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Functioning of Young Individuals with Upper Limb Reduction Deficiencies

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Chapter 4

Adaptive devices in youngsters with upper limb reduction deficiencies: use and satisfaction

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Abstract

Objective

To evaluate the use, satisfaction, and social adjustment with adaptive devices (ADs) compared with prostheses in youngsters with upper limb reduction deficiencies (ULRD).

Methods

In a cross-sectional study, youngsters with ULRD (2-20 years) and their parents responded to a questionnaire evaluating the participants' characteristics, difficulties encountered, and preferred solutions for activities, use, satisfaction, and social adjustment with ADs versus prostheses. The Quebec User Evaluation of Satisfaction with assistive Technology and a subscale of Trinity Amputation and Prosthesis Experience Scales were used.

Results

Of 218 participants, 58% were boys, 87% had transversal ULRD, 76% with past/present use of ADs and 37% with past/present use of prostheses. Youngsters (> 50%) had difficulties in performing activities. Of 360 ADs, 43% were used for self-care (using cutlery), 28% for mobility (riding a bicycle), and 5% for leisure activities. Prostheses were used for self-care (4%), mobility (9%), communication (3%), recreation and leisure (6%), and work/employment (4%). The preferred solution for difficult activities was using unaffected and affected arms/hands and other body parts (> 60%), ADs (< 48%), and prostheses (< 9%). Satisfaction and social adjustment with ADs were greater than with prostheses ($P < 0.05$).

Conclusion

Youngsters with ULRD are satisfied and socially well-adjusted with ADs. ADs are good alternatives to prostheses.

Introduction

Youngsters with upper limb reduction deficiency (ULRD) are generally able to perform activities of daily living (ADL)[1-3] by finding solutions to facilitate difficulties in activities and participation.[2] However, some ADL pose more functional limitations; for example, lifting heavy objects, doing/engaging in sports, cycling or driving.[3,4] Although prostheses are usually prescribed for activity limitations,[5-7] they are rejected by 35% to 45% of youngsters with ULRD[8] due to the weight, lack of functional gain and loss of or reduced sensory feedback, or discomfort of the prostheses.[3,9-12] Terminal devices, mountable on a prosthesis,[4] seem to be specifically useful to children with ULRD for activities that require bimanual handling (lifting barbells, playing the violin).[13] Disadvantages of these prosthetic terminal devices are that they are expensive.[13] Depending on the activity requirements (e.g., a more stable fixation to the residual limb), the terminal device might require construction of a new prosthesis/socket to accommodate the terminal device.[13] Moreover, some youngsters (or their relatives) develop homemade adaptations which meet their needs better.[13]

Much of the functionality of youngsters with ULRD, irrespective of the use of a prosthesis, is enabled by adaptive movements with the residual limb, head/face, trunk, or legs,[14] use of creative solutions (e.g., ligature of the object on the residual limb with tape) or by adaptive (or assistive) devices (ADs).[2] An AD is defined as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."[15] In this study, prostheses or terminal devices, mounted on a prosthesis, were not considered ADs.

In the Netherlands, it is common practice for rehabilitation teams, comprising of physicians, therapists, and technicians, to design and provide youngsters with ULRD, using or not using a prosthesis, with some kind of AD. These devices that improve independence of youngsters in ADL[16] are usually lightweight, easy to don and doff, and are inexpensive. Recently, we evaluated the activities and participation,[2] prosthetic use, and rehabilitation care[3] of youngsters with below-elbow ULRD. It was found that many youngsters with below-elbow ULRD use ADs for activities like eating, cycling, doing/engaging in sports or playing a musical instrument.[2,3] To our knowledge, no study has been performed that has addressed the use and satisfaction with ADs in youngsters with ULRD and compared users' satisfaction with ADs to satisfaction with a prosthesis. Furthermore, youngsters with below-elbow ULRD

seem to wear prostheses to achieve social acceptance and integration,[3] but the social adjustment of youngsters with ULRD using ADs is unknown.

The first aim of this study is to evaluate the use of ADs for facilitating difficult ADL in youngsters with ULRD and the factors influencing the use of ADs and prostheses. The second aim of the study is to compare the use, satisfaction, and social adjustment with ADs with that of prostheses.

Methods

A cross-sectional study using questionnaires was used for data collection (between February and June 2013). Ethical approval was granted by the University Medical Ethical Committee (M12.128982). Informed consent was obtained from all participants: from the parent/guardian of a child younger than 12 years old (y/o), from the parent and the child if the youngster was 12-17 y/o, and from the adolescent only when older than 17 y/o. The participants were informed that data would be anonymized and access to data was restricted only to involved researchers. After returning the fully completed questionnaire, the participant received a gift voucher (EUR 10).

Recruitment and participants

Participants were recruited from nine rehabilitation centers scattered throughout the Netherlands. In addition, the adoption association of children with birth defects sent invitation emails with a link to the electronic version of the questionnaire as an extra reminder to participate (most adopted children with ULRD were also registered in rehabilitation centers participating in this study).

Participants, both youngsters and parents of children younger than 12 y/o, were included if the youngster was between 2 and 20 y/o, and had a transverse (wrist and hand, below-elbow, or above/through-elbow level) or longitudinal ULRD. Complex symbrachydactyly (very short webbed fingers) was also included under transversal reduction deficiencies. Participants that had mild symbrachydactyly or ULRD at the hand level with less than four fingers missing were excluded as they were considered having low-degree of

functional impairment. Participants with poor command of the Dutch language were excluded.

Procedure

An electronic and a paper version of the questionnaire were available. Envelopes containing the paper version of the questionnaire, an invitation letter from the physician, an information letter from the researchers, and an informed consent form ware mailed to participating rehabilitation centers. Because researchers did not have access to the personal details of the participant, the questionnaire may have been sent twice to the some participants. Participating centers were asked to select current patients, not those that had been transferred to another center to avoid doubles, and mail the envelops with the information and questionnaires.

Parents of children between 2 and < 7 y/o, parents together with youngsters of 7 - <13 y/o, and adolescents of 13-20 y/o were instructed to complete the questionnaire.

The questionnaire

Data about youngsters with ULRD and ADs, collected from our previous studies,[2,3] were used to develop the main part of the 37-item questionnaire. Besides participants' characteristics, the questionnaire assessed difficulties in ADL, types of and use of ADs (maximum five ADs), prostheses use in daily activities, user's satisfaction with ADs and prostheses, social adjustment with ADs and prostheses, and suggestions for improving the use of ADs. The majority of questions had a single answer option (Likert scale or 'yes/no' answers). Two questions had multiple answer options (Appendix 1).

To evaluate user's satisfaction with ADs compared with prosthesis, the Dutch version of Quebec User Evaluation of Satisfaction with assistive Technology (D-Quest) questionnaire was used.[17] The D-Quest evaluates two domains: satisfaction with the device and satisfaction with the rehabilitation services. Questions on satisfaction with rehabilitation services had to be answered only by participants with ADs that were developed in a rehabilitation center or an orthopedic workshop.

Social adjustment was assessed with a subscale of the Trinity Amputation and Prosthesis Experience Scales questionnaire (TAPES, upper limb version, social adjustment subscale of psychosocial adjustment).[18,19] The minimum-maximum scores for TAPES social adjustment

subscale are 0 to 4 points (poor to very good social adjustment). Studies on internal consistency and factor structure recommended the use of TAPES in upper limb amputees.[18,20] Participants were asked to choose their most important AD and then answer the questions about their satisfaction and social adjustment with that device and the prosthesis (if applicable, Appendix 1). 'Most important' AD could be related to its necessity in performing activities or its frequent use, independent of appearance. A professional editor with extensive experience in developing questionnaires for pediatric and adult population reviewed the questionnaire. The wording of D-Quest and TAPES questions was simplified to enable understanding of the questions by participants of all ages. The entire questionnaire was tested for clarity and conciseness on a group of four parents and seven unimpaired children. Two independent healthcare professionals (an occupational therapist and a prosthetist) working with children with ULRD reviewed the questionnaire. The comments and suggestions received were used to improve the formulation of the questions.

Statistical analysis

The ADLs were grouped according to the International Classification of Functioning, Disability and Health (ICF) component – activities and participation – and its domains: self-care, mobility (including transportation methods), communication, recreation and leisure, and domestic life and work/employment.[21] Domestic life and work/employment were considered as one category. Age was grouped (2 - <7, 7 - <13, and 13 - 20 y/o) to give insight into the difficulties experienced in ADL and ADs by different age groups.

To facilitate analyses and data presentation, answers regarding experienced difficulties in ADL and satisfaction with the appearance of the most important AD/prosthesis were dichotomized (Appendix 1). 'Yes/no' variables were created for each preferred solution used in ICF domains, denoting use or non-use of the respective solution.

Binary logistic regressions were used to determine the factors predicting the use of ADs or prostheses. The outcome variables were past/present use of ADs and past/present use of prostheses. The predictor variables were age, gender, number of difficulties in ADL, ULRD type, and level of transversal ULRD (0 = above/through-elbow, 1 = below-elbow; wrist and hand level was excluded because prostheses are not prescribed for youngsters with this ULRD level).

Paired t-tests were used to determine the differences in satisfaction (D-Quest) and social adjustment (TAPES) between most important AD and prosthesis. According to D-Quest instructions for analysis,[22] overall and per-item satisfactions were assessed.

The significance level was set at $P \leq 0.05$ and all analyses were performed with IBM SPSS Statistics for Windows, version 20.0 (IBM Corp., 2011, Armonk, NY, USA, www.spss.com).

Results

In total, 523 questionnaires were sent out and 223 (43%) were returned. Two uncompleted questionnaires were returned due to outdated address and three questionnaires were excluded because the participants did not meet the inclusion criteria (mild symbrachydactyly, radioulnar synostosis, and partially amputated little finger). In total, 218/523 (42%) questionnaires were included, of which 30 questionnaires were completed online. All participants gave consent and no double completion of the questionnaires was identified.

Participants' characteristics and ADs/prostheses use

Of the 218 participants, 58% were boys, 52% had a below-elbow ULRD, 76% with past/present use of an AD and 37% with past/present use of a prosthesis (Table 1). The reasons for never using an AD were being able to perform any ADL independently (60% of n = 52), performing activities in a different manner (35%), being currently too young (10%), or never having heard about ADs (4%). Of the youngsters with past/present use of an AD (n = 166), 27% had one AD, 45% had two ADs, and 28% had three or more. In total, 360 ADs were used by the participants (Table 2, Figure 1).

Table 1. Characteristics of the participants, upper limb reduction deficiency, and use of adaptive device and prostheses for the age groups and the total group

Characteristics	2-<7 y/o n (%)	7-<13 y/o n (%)	13-20 y/o n (%)	Total n (%)
Total	64 (29.4)	102 (46.8)	52 (23.9)	218 (100.0)
Boys	43 (19.7)	56 (25.7)	28 (12.8)	127 (58.3)
Girls	21 (9.6)	46 (21.1)	24 (11.0)	91 (41.7)
ULRD location				
Unilateral	61 (28.0)	94 (43.1)	46 (21.1)	201 (92.2)
Bilateral	3 (1.4)	8 (3.7)	6 (2.8)	17 (7.8)
ULRD type				
Longitudinal	13 (6.0)	11 (5.0)	5 (2.3)	29 (13.3)
Transversal	51 (23.4)	91 (41.7)	47 (21.6)	189 (86.7)
Above/through-elbow	3 (1.4)	6 (2.8)	7 (3.2)	16 (7.3)
Below-elbow	30 (13.8)	53 (24.3)	30 (13.8)	113 (51.8)
Wrist and hand	18 (8.3)	32 (14.7)	10 (4.6)	60 (27.5)
Past/present use of ADs (total)	41 (18.8)	90 (41.3)	35 (16.1)	166 (76.1)
Currently using	37 (17.0)	70 (32.1)	25 (11.5)	132 (60.6)
Not using anymore	4 (1.8)	20 (9.2)	10 (4.6)	34 (15.6)
ADs never used	23 (10.6)	12 (5.5)	17 (7.8)	52 (23.9)
Past/present use of prosthesis (total)	15 (6.9)	33 (15.1)	32 (14.7)	80 (36.7)
Currently using	7 (3.2)[a]	13 (6.0)[a]	10 (4.6)	30 (13.8)
Myoelectric	2 (0.9)	5 (2.3)	5 (2.3)	12 (5.5)
Body-powered	3 (1.4)	3 (1.4)	2 (0.9)	8 (3.7)
Cosmetic/passive	1 (0.5)	3 (1.4)	3 (1.4)	7 (3.2)
Others	0	1 (0.5)	0	1 (0.5)
Not using anymore	8 (3.7)	20 (9.2)	22 (10.1)	50 (22.9)
Myoelectric	0	6 (2.8)	12 (5.5)	18 (8.3)
Body-powered	0	3 (1.4)	1 (0.5)	4 (1.8)
Cosmetic/passive	8 (3.7)	9 (4.1)	8 (3.7)	25 (11.5)
Others	0	2 (0.9)	1 (0.5)	3 (1.4)
Prosthesis never used	49 (22.5)	69 (31.7)	20 (9.2)	138 (63.3)
AD and prosthesis	9 (4.1)	26 (11.9)	21 (9.6)	56 (25.7)
AD and no prosthesis	32 (14.7)	64 (29.4)	14 (6.4)	110 (50.5)
No AD nor prosthesis	17 (7.8)	5 (2.3)	6 (2.8)	28 (12.8)
Prosthesis and no AD	6 (2.8)	7 (3.2)	11 (5.0)	24 (11.0)

Abbreviations and notations: AD(s), adaptive device (s); ULRD, upper limb reduction deficiency; n, number of children.
[a]Prosthesis type not specified in one participant.

Table 2. Difficulties and adaptive devices used in activities of daily living grouped into ICF domains for the age groups and the total group

ICF domains and ADL	Difficulties				ADs used			
	2-<7 y/o n/v (%)	7-<13 y/o n/v (%)	13-20 y/o n/v (%)	Total n/v (%)	2-<7 y/o n (%)	7-<13 y/o n (%)	13-20 y/o n (%)	Total ADs n (%)
Self-care								
Using cutlery	47/64 (73.4)	81/102 (79.4)	30/52 (57.7)	158/218 (72.5)	34 (9.4)	95 (26.4)	27 (7.5)	156 (43.3)
Dressing or undressing	34/61 (55.7)	16/102 (15.7)	4/52 (7.7)	54/215 (25.1)	3 (0.8)	7 (1.9)	3 (0.8)	13 (3.6)
Tooth brushing	3/62 (4.8)	3/100 (3.0)	0/52	6/214 (2.8)	-	-	-	-
Self-washing/taking a shower	13/58 (22.4)	15/101 (14.9)	1/52 (1.9)	29/211 (13.7)	-	2 (0.6)	1 (0.3)	3 (0.8)
Using the toilet	17/58 (29.3)	8/102 (7.8)	3/52 (5.8)	28/212 (13.2)	-	3 (0.8)	-	3 (0.8)
Tying shoelaces	35/41 (85.4)	56/95 (58.9)	22/51 (43.1)	113/187 (60.4)	-	1 (0.3)	-	1 (0.3)
Mobility								
Riding a bicycle	33/59 (55.9)	19/101 (18.8)	10/52 (19.2)	62/212 (29.2)	34 (9.4)	52 (14.4)	15 (4.2)	101 (28.1)
Riding a moped, a scooter or driving	-	-	9/22 (40.9)	9/22 (40.9)	-	-	5 (1.4)	5 (1.4)
Communication								
Writing	8/50 (16.0)	18/102 (17.6)	3/52 (5.8)	29/204 (14.2)	1 (0.3)	2 (0.6)	1 (0.3)	4 (1.1)
Using a computer keyboard	14/39 (35.9)	33/100 (33.0)	7/52 (13.5)	54/191 (28.3)	-	2 (0.6)	6 (1.7)	8 (2.2)
Recreation and leisure								
Doing/engaging in sports	19/49 (38.8)	40/102 (39.2)	15/51 (29.4)	74/202 (36.6)	1 (0.3)	9 (2.5)	5 (1.4)	15 (4.2)
Handcrafting	34/64 (53.1)	46/102 (45.1)	12/49 (24.5)	92/215 (42.8)	3 (0.8)	5 (1.4)	-	8 (2.2)
Playing a musical instrument	15/19 (78.9)	43/61 (70.5)	14/24 (58.3)	72/104 (69.2)	1 (0.3)	8 (2.2)	5 (1.4)	14 (3.9)
Leisure activities[a]	37/62 (59.7)	41/101 (40.6)	13/48 (27.1)	91/201 (43.1)	4 (1.1)	13 (3.6)	2 (0.6)	19 (5.3)
Domestic life and work/employment								
Household activities[b]	9/17 (52.9)	38/59 (64.4)	28/50 (56.0)	75/126 (59.5)	1 (0.3)	2 (0.6)	4 (1.1)	7 (1.9)
Work/employment[c]	0/1	2/5 (40.0)	10/38 (26.3)	12/44 (27.3)	-	-	-	-
Other or multiple ADL	1/1 (100.0)	6/6 (100.0)	-	7/7 (100.0)	-	3 (0.8)	-	3 (0.8)
Total ADs					82 (22.8)	204 (56.7)	74 (20.6)	360 (100)

Abbreviations and notations: ICF, International Classification of Functioning Disability and Health; ADL, activities of daily living; AD(s), adaptive device(s); n, number of children having difficulties or number of ADs; v, number of valid answers; "-", no difficulty or no AD was reported.
Percentages for 'Difficulties' represent the youngsters having difficulties (n) out of the number or valid responses per age category (v); percentages for 'Used ADs' are calculated from the total number of ADs n=360.
[a]Leisure activities such as playing Wii, jumping rope, or swinging.
[b]Household activities such as peeling potatoes, washing, make pancakes.
[c]Work such as (part-time) job, summer job.

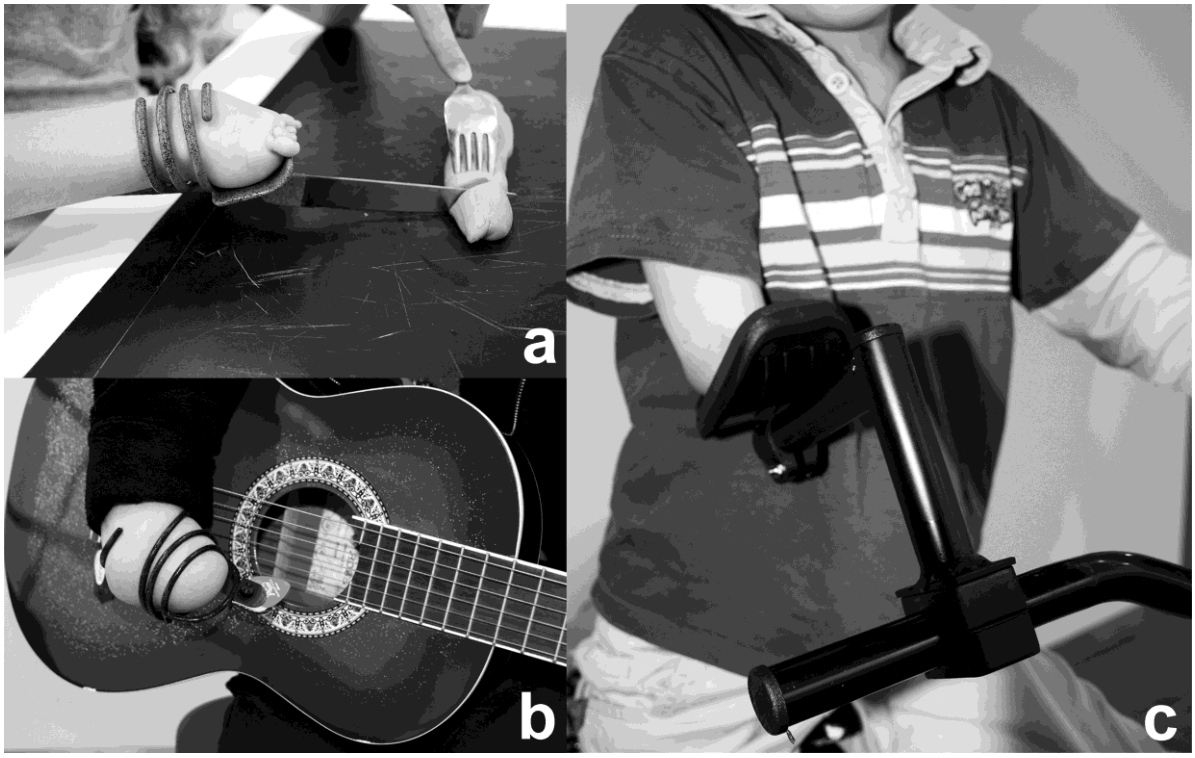

Figure 1. Examples of adaptive devices used for (a) eating, (b) playing a musical instrument, and (c) riding a bike (photos: © De Hoogstraat Orthopedietechniek, UMCU, Utrecht)

Difficulties in ADL/ described types of ADs. More than half of participants experienced difficulties in the ICF domains self-care (using cutlery [73%] and tying shoelaces [60%]), in recreation and leisure (playing a musical instrument [69%]), and in household activities (60%) (Table 2). Of the 360 ADs, 43% were used for eating with cutlery, 28% for riding a bicycle, 5% for leisure activities, 4% for doing/engaging in sports, and 4% for playing a musical instrument (Table 2). Most ADs were used always or very often (64% of ADs).

Of 166 participants that have used ADs in the past or were still using ADs, 165 participants described *a most important AD* for them. A number of 56/166 participants have used a prosthesis in the past or were currently using a prosthesis as well. Due to non-use of his AD, one participant did not complete this section of the questionnaire. The most important AD was mostly used for the ADL using cutlery (52% of 165), riding a bicycle (33%), doing/engaging in sports (4%), dressing or undressing (3%) or playing a musical instrument (3%).

Participants acquired their most important AD and prostheses when they were younger than 5 y/o (46%, 61%, respectively) or between 5 and 8 y/o (37% and 18%, respectively). The most important AD was used for several consecutive years, on average for

4.6 years, SD = 3.2 (67% of participants) or it was used for less than three months (12%). Prostheses were used for several consecutive years, on average for 6.7 years, SD = 4.2 (30%), less than three months (25%), and 18% used intermittently their prosthesis. The most important AD as well as prostheses were used everywhere (44%, 41%, respectively), at home only (34% and 9%), or at home and in environments with acquaintances–school, family or friends (19% and 34%).

Manufacturer of ADs. The ADs were mostly made in rehabilitation centers by specialized professionals (79% of 360 ADs), particularly by rehabilitation teams comprising a technician and an occupational therapist or physiotherapist. The remaining ADs were developed by the youngsters themselves or by a family member (16%), or were acquired from other sources (4%).

ADs use in the context of preferred solutions to facilitate difficult ADL. The most preferred solution to facilitate difficult ADL was using unaffected and affected upper limbs and other body parts (39%-96% of participants in different ADL, Table 3). A considerable number of youngsters preferred ADs (12%-48%). The most preferred solution for using cutlery was using ADs (46%, Table 3). External help was preferred more than ADs for tying shoelaces (46% of respondents) and for domestic life and work/employment activities (21%). Prostheses were the least preferred solution (over all ICF domains ≤ 9%).

Table 3. Preferred solutions for performing activities of ICF domains

ICF domains (v)	Preferred solutions			
	AD n (%)	Prosthesis n (%)	Hands n (%)	Help n (%)
Self-care[a] (214)	103 (48.1)	9 (4.2)	186 (86.9)	106 (49.5)
Using cutlery (211)	96 (45.5)	6 (2.8)	82 (38.9)	27 (12.8)
Tying shoelaces (169)	2 (1.2)	6 (3.6)	83 (49.1)	78 (46.2)
Mobility[a] (191)	58 (30.4)	17 (8.9)	117 (61.3)	2 (1.0)
Riding a bicycle (186)	54 (29.0)	17 (9.1)	113 (60.8)	2 (1.1)
Communication[a] (181)	7 (3.9)	6 (3.3)	174 (96.1)	3 (1.7)
Recreation and leisure[a] (210)	40 (19.0)	13 (6.2)	183 (87.1)	36 (17.1)
Playing a musical instrument (75)	16 (21.3)	1 (1.3)	56 (74.7)	2 (2.7)
Domestic life and work/employment[a] (128)	16 (12.4)	5 (3.9)	90 (69.8)	27 (20.9)

Abbreviations and notations: AD, adaptive device; Hands, unaffected hand and affected arm and/or other body parts; Help, with help from somebody; n, number of children; v, total number of children with valid responses in each activity or ICF domain. The answer category 'sometimes adaptive device or prosthesis' was not presented in the table due to low numbers. ICF, International Classification of Functioning; 'not applicable' answers for all of the activities within an ICF-domain were excluded.
Percentages are calculated from the total number of valid responses (v).
[a]Each solution used per ICF domain was coded as a dichotomous variable (yes, when at least one of the activities contributing to the ICF domain was performed with the corresponding solution).

Factors influencing the use of ADs/prostheses. Results of logistic regression showed that when controlling for age, gender, and ULRD type, the ADs were more likely to have been used when experiencing difficulties in ADL (OR = 1.17, Table 4).

In the case of youngsters with transversal ULRD at a more proximal level than wrist and hand level, an AD was more likely to have been used by youngsters experiencing difficulties in ADL (OR = 1.25). ADs were less likely to have been used by youngsters with transversal ULRD if they have had a prosthesis (OR = 0.36).

Prostheses were more likely to have been used by older youngsters (OR = 1.14) and less likely to have been used by boys (OR = 0.44), and by youngsters that have had an AD (OR = 0.35, Table 4).

Satisfaction and social adjustment with ADs versus prostheses

Satisfaction with most important AD compared with satisfaction with prostheses (D-Quest). Participants were more satisfied with their most important AD than with prosthesis ($P < 0.01$, Table 5). Higher satisfaction was recorded for their most important AD compared with prosthesis (Table 5) in the D-Quest items: dimensions, weight, adjustment, ease of use, and comfort ($P < 0.01$). No difference was seen between the satisfaction with rehabilitation services for most important AD and the satisfaction with rehabilitation services for prostheses.

Participants were (very) satisfied with the appearance of their most important AD (87%) and of the prosthesis (66%; question not part of D-quest).

Social adjustment with most their important AD compared with social adjustment with prostheses. The social adjustment with the AD was significantly higher than with the prosthesis ($P = 0.044$, Table 5).

Suggestions for improving the use of ADs

Of 218 participants, 48% wished for special online facilities to exchange ideas about ADs and to see the ADs; 36% wanted more information about AD types; 25% suggested that more workshops and/or meetings about ADs should be organized together with other children with ULRD. Other suggestions were more colors (18%), more diversity for ADs (17%), more ADs

for sports (11%; e.g., for hockey, horseback riding, or judo), a short training for ADs (8%), and cheaper ADs (6%).

Table 4. Results of logistic regression with the use of adaptive devices or prostheses as outcome variable and the participants' characteristics as predictors

Past/present use of ADs or prostheses	Yes	No				
	No. (%) or Mean (SD)	No. (%) or Mean (SD)	β (SE)	P	OR	95% CI
ADs[a] (all ULRD levels)	n=166	n=52				
Age (centered at 2 y/o)	8.3 (4.3)	7.9 (6.0)	0.03 (0.04)	0.374	1.03	(0.96; 1.11)
Gender (male)	97 (58.4)	30 (57.7)	0.07 (0.33)	0.841	1.07	(0.56; 2.05)
Number of difficulties in ADL	4.7 (3.0)	3.6 (2.8)	0.16 (0.06)	0.010*	1.17	(1.04; 1.32)
ULRD type (transversal)	147 (88.6)	42 (80.8)	0.73 (0.45)	0.104	2.08	(0.86; 5.05)
Constant			-0.42 (0.62)	0.505	0.66	(0.19; 2.24)
ADs[a,b] (ULRD levels higher than the wrist)	n=99	n=30				
Age (centered at 2 y/o)	8.6 (4.5)	8.9 (6.0)	0.05 (0.05)	0.315	1.05	(0.95; 1.16)
Gender (male)	57 (57.6)	16 (53.3)	-0.14 (0.45)	0.763	0.87	(0.36; 2.12)
Number of difficulties in ADL	4.8 (3.0)	3.1 (2.6)	0.23 (0.10)	0.017*	1.25	(1.04; 1.51)
Transversal ULRD (below-elbow)	85 (85.9)	28 (93.3)	0.11 (0.87)	0.897	1.12	(0.21; 6.10)
Past/present use of prostheses	49 (49.5)	22 (73.3)	-1.02 (0.52)	0.048*	0.36	(0.13; 0.99)
Constant			0.50 (1.13)	0.658	1.65	(0.18; 15.23)
Prostheses[a,b] (ULRD levels higher than the wrist)	n=71	n=58				
Age (centered at 2 y/o)	10.0 (4.9)	7.1 (4.4)	0.13 (0.04)	0.004*	1.14	(1.04; 1.24)
Gender (male)	33 (46.5)	40 (69.0)	-0.82 (0.40)	0.038*	0.44	(0.20; 0.96)
Number of difficulties in ADL	3.8 (3.0)	5.0 (2.9)	-0.04 (0.07)	0.513	0.96	(0.84; 1.09)
Past/present use of ADs	49 (69.0)	50 (86.2)	-1.06 (0.51)	0.038*	0.35	(0.13; 0.95)
Constant			0.64 (0.65)	0.324	1.90	(0.53; 6.79)

Abbreviations and notations: AD(s), adaptive device(s); ULRD, upper limb reduction deficiency; No., number of children; n, total number of children; β, coefficient showing weighting of each factor in the model; SE, standard error; P, value showing the significance; OR, odds ratio; 95% CI, the 95 % confidence interval for the estimated odds ratio; 'ever used', devices that were used in the past or currently; y/o, years old.
Percentage are calculated from the total number of 'Yes' (past/present use of ADs or past/present use of prostheses) or 'No' category (never used ADs/never used prostheses).
[a]Age was centered at 2 y/o. Reference categories for gender–female, for ULRD type–longitudinal ULRD, for transversal ULRD–above/through-elbow level.
[b]Included: 22 participants were with past/present use of a prosthesis, 50 participants were with past/present use of an AD, 49 participants were with past/present use of both, and 8 participants used neither. Excluded: transversal ULRD at the wrist and hand level because prostheses are not prescribed for children with wrist or hand ULRD; and longitudinal ULRD. Due to low cell numbers, the variable 'Transversal ULRD' has been excluded from the analysis conducted for prosthetic use.
*Significant P-value.

Table 5. Satisfaction (D-Quest)[a] and social adjustment (TAPES) with adaptive devices and prostheses

Questionnaire		AD Mean (SD)	Prosthesis Mean (SD)	Mean difference (SD)	P-value
D-Quest Devices[b]	(n=46)	4.30 (0.45)	3.28 (0.82)	1.02 (0.87)	<0.001*
Dimensions	(n=49)	4.49 (0.58)	3.12 (1.30)	1.37 (1.45)	<0.001*
Weight	(n=48)	4.46 (0.50)	2.71 (1.13)	1.75 (1.25)	<0.001*
Adjustment	(n=43)	4.09 (0.72)	3.26 (1.09)	0.84 (1.17)	<0.001*
Safety	(n=45)	4.33 (0.60)	4.11 (0.88)	0.22 (0.79)	0.067
Durability	(n=45)	4.20 (0.87)	3.98 (0.92)	0.22 (1.17)	0.208
Ease of use	(n=47)	4.28 (0.85)	2.74 (1.33)	1.53 (1.44)	<0.001*
Comfort	(n=47)	4.17 (0.67)	3.47 (1.12)	0.70 (1.30)	0.001*
Effectiveness	(n=47)	4.49 (0.72)	3.02 (1.29)	1.47 (1.49)	<0.001*
D-Quest Rehabilitation services[b]	(n=37)	4.21 (0.57)	4.19 (0.62)	0.02 (0.67)	0.839
Service delivery	(n=38)	4.26 (0.86)	4.11 (0.92)	0.16 (1.17)	0.413
Repairs and servicing	(n=31)	4.19 (0.60)	4.16 (0.64)	0.03 (0.60)	0.768
Professional services	(n=38)	4.29 (0.65)	4.32 (0.77)	-0.03 (0.72)	0.822
Follow-up	(n=37)	4.24 (0.49)	4.22 (0.67)	0.03 (0.60)	0.786
TAPES Social adjustment (n=45)		3.28 (0.68)	3.12 (0.86)	0.16 (0.50)	0.044*

Abbreviations and notations: AD, (most important) adaptive device; SD, standard deviation; n, number of participants with valid responses; D-Quest, Dutch version of Quebec User Evaluation of Satisfaction with assistive Technology; TAPES, Trinity Amputation and Prosthesis Experience Scales.
[a]Overall and per D-Quest item scores were presented; n=165 participants completed the D-Quest (one 18-20 y/o participant had recall difficulties on D-Quest).
[b]Overall score. In this analysis, participants that responded to ≥6 questions in the Devices section and ≥3 questions in the Rehabilitation services section (according to D-Quest instructions for analysis) were included.[22]
*Significant P-value.

Discussion

This study investigated for the first time, the use of, satisfaction, and social adjustment with adaptive devices versus prostheses in youngsters with ULRD. More than half of the youngsters with ULRD reported having difficulties in ADL for which they used different solutions. Along with preferentially using their unaffected and affected upper limbs and other body parts as a natural process in motor learning,[23] youngsters with ULRD used ADs much more than prostheses. The ADs were important for performing ADL of self-care (using cutlery), enabling mobility (riding a bicycle), or for recreation and leisure, and were mainly developed by healthcare professionals. ADs appeared to be especially useful in children who encounter many difficulties in ADL performance. Satisfaction with the ADs was greater than satisfaction with prostheses. No difference was seen between ADs and prostheses regarding satisfaction with rehabilitation services. Social adjustment was somewhat better with the ADs than with the prostheses.

Difficulties in ADL and use of ADs. Activities posing difficulties in youngsters with ULRD are those requiring both hands to maintain a stable position.[24] Our participants reported difficulties in activities requiring bilateral manipulation such as using cutlery to cut the food

while stabilizing it with a fork, tying shoelaces, playing a musical instrument, or riding a bike. The latter has to be performed with both arms for stability and safety reasons. The use of ADs has been recommended for children experiencing difficulties in activities, and to improve participation,[16] to diminish physical effort, or to reduce the risk of injuries.[24] However, the heterogeneity in terminology, data-collection methods, and outcomes in studies about assistive devices in youngsters with impairments[16] hampers comparison with our results. The studies about ADs were mostly descriptions of devices or rehabilitation with devices.[4,13,25,26] Data on actual use and satisfaction with ADs in children with ULRD were lacking.

A variety of assistive devices has been described in adults (≥18 y/o) with different impairments.[17] Assistive devices were used for personal care (19% of 2002 participants), communication (5%), mobility (9%), and 15% had prostheses as prostheses were considered assistive devices in that study.[17] People with cerebral palsy (CP) use upper-limb assistive devices for personal care and communication (between 23% and 79% of people with CP).[26] Although many of the devices resembled the devices in our study such as pencil holders, adapted cutlery or dressing sticks, the people with CP had bilateral upper-limb impairments and were older (14-77 y/o) than our participants. Regardless of differences in the literature and types of impairment, ADs seem to be used predominantly for personal care (self-care) as found in our study as well.

The majority of youngsters with ULRD in the present study, 80% of 166 participants, have either used or are currently using ADs. On the contrary, in persons with CP, 46% abandoned assistive devices after the first year of usage due to improvement in function or other alternatives found.[26] Another study also reported lower rates for abandonment of assistive devices in impaired Dutch persons when compared with the rates in the literature.[27] The authors speculated that a number of the investigated devices were difficult to obtain and that rejection of hard-to-obtain assistive devices is less likely to occur.[27] Such an explanation is not pertinent to our users because obtaining an AD in the Netherlands is an easy and inexpensive process; often covered by insurance companies.

Preferred solutions for ADL. Although our participants experienced difficulties in ADL, their preferred solution to facilitate ADL performance was using their unaffected and affected upper limbs or other body parts. This finding supports the literature outcomes suggesting that youngsters with ULRD can perform most ADL without help accessories (prostheses).[1,28]

What seems to contribute to the use of ADs is the number of difficulties experienced in ADL: the more difficulties, the higher the chance of using ADs according to our findings. Although not found in our study, the use or non-use of ADs by youngsters with ULRD also seems to be task- and age-specific according to clinical observations. As such, ADs are used especially during the life phases when new skills are learned. For example, youngsters need an AD when learning to ride a bike. At an older age, they develop skills that allow them to ride a bike without an AD. Note that there are some cultural specifics regarding the ADs used for mobility because riding a bicycle is a common and popular means of transport in the Netherlands.

Concerning the use of prostheses, a higher chance for their use was predicted by an increase in age. However, this increase in the use of prostheses with age increase contradicts other findings.[29] From the literature on the use of prostheses, it is known that youngsters with ULRD, using or not using prostheses, behave differently. At puberty, some use a prosthesis to appear 'bodily-complete' or for functionality purposes while other youngsters who used a prosthesis reject it because of people staring at them, poor cosmesis or lack of functional gain.[3,9,12] The use of ADs and the use of prostheses seem to inter-influence each other. Youngsters with more proximal ULRD than the wrist are less likely to use ADs if they use a prosthesis and vice versa. When interpreting these results, consider that our analyses on factors influencing the use of ADs or prostheses included participants (n = 49) with past/present use of both. These participants were included once in the analysis as users of ADs and once as users of prosthesis, indicating that these analyses are not independent. Future studies should look at the abandonment of ADs and the influence of socio-emotional development of youngsters with ULRD on the use of ADs as well.

Satisfaction with ADs compared with satisfaction with prostheses. Our results demonstrated that satisfaction with ADs was significantly greater than satisfaction with prostheses in several aspects: dimensions, weight, adjustment, ease of use, comfort, and effectiveness (Table 5). These aspects have been reported as reasons for prosthesis rejection in previous research.[3,9-12] ADs seem to provide the user with the needed functionalities and appropriate device properties. As such, healthcare professionals working with youngsters with ULRD should regard the provision of ADs as an efficient treatment. Furthermore, ADs are a cost-efficient option because they do not require sophisticated materials and technologies or extended training programs as is the case with prostheses.[6,7,30-32] Manufacturing ADs is also a relatively fast process necessitating minimum waiting time for the users.

Social adjustments. Considering our previous findings that youngsters with below-elbow ULRD use prostheses to avoid being stared at,[3] we expected satisfaction with prostheses to be better than satisfaction with ADs. However, this was not the case in the current participants, which might be explained by greater gain of ADL independence when using ADs compared with prostheses. Being independent in activities gives youngsters a sense of fulfillment and equality with their peers.[33,34] As such, ADs contribute to some extent to the normality of youngsters with ULRD. The importance of normality in impaired youngsters has been stressed previously in the literature.[33-35]

Curiously, compared with their peers, youngsters with ULRD appear to be overall happier,[1] perceive their physical appearance as their peers perceive it,[36] and are similarly psychosocially adjusted.[37] Using a prosthesis was suggested to be beneficial for psychosocial adjustment.[37] Although we did not evaluate psychosocial adjustment extensively, our results seem to support the above-mentioned findings. Youngsters with ULRD are socially well adjusted, and ADs as well as prostheses may contribute to that.

Clinical implications and suggestions. The findings of this study have highlighted the impact of the use of ADs in youngsters with ULRD, which advocates for confidently introducing ADs in the current treatment options of youngsters with ULRD. Online facilities with visual presentations and more information about different types of ADs should be created as suggested by our participants. Importantly, healthcare professionals should clarify the functional benefits of both ADs and prostheses to rule out unrealistic expectations.[3]

Researchers should also assess the differences between ADs and prostheses regarding compensatory movements and overuse complaints.

A limitation of this study might be the somewhat low response rate. Possibly, youngsters with ULRD were disinterested in participating because they generally function well and do not perceive themselves as impaired. However, a decreasing trend for response rates to surveys in the last decade has been reported.[38,39]

Youngsters with bilateral ULRD might have had different functional needs, but a separate analysis was not possible because the group with bilateral ULRD was too small, n=17. However, the results of post-hoc analyses (regression and t-tests), conducted only with the unilateral ULRD group, did not display substantial differences compared with the results in Table 4 and Table 5 (Appendix 2, the T-test results were similar to those in Table 5).

Although the questionnaire was tested in a pilot environment and an experienced editor and healthcare professionals were consulted, it was unfeasible to test its validity and reliability. Further studies are required to validate the questionnaire as well as the D-Quest and TAPES questionnaires in the Dutch pediatric patients.

Participants' responses may have suffered from recall bias, especially in those who were not using their ADs or prostheses anymore.

In conclusion, youngsters with ULRD used ADs more than they used prostheses for facilitating ADL difficulties. The satisfaction with the device-related aspects of ADs was greater than satisfaction with prostheses. Social adjustment of children with ULRD was good. Between ADs and prostheses, youngsters with ULRD were somewhat better socially adjusted with ADs. Therefore, healthcare professionals should advance ADs as alternative to prosthetic treatment.

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Appendices

Appendix 1. Description of the questionnaire

Theme	Questions	Response options	Grouping for the analysis
Participants' characteristics	Age	Fill out: Day/Month/Year	2-<7 y/o; 7-<13 y/o; and 13-20 y/o
	Gender	Girl or boy	
	Education	List of 11 types of education (from daycare to university)	
	Type of ULRD	Images demonstrating transversal or longitudinal ULRD and self-description of the affected arm	
	Level of ULRD	Six levels for each left/ right hand	
Functionality difficulties	ADL combined in ICF domains: *self-care*: using cutlery, dressing or undressing, tooth brushing, self-washing/taking a shower, using the toilet, tying shoelaces; *mobility*: riding a bicycle, riding a moped, a scooter or driving; *communication*: writing, using a computer keyboard; *recreation and leisure:* doing/engaging in sports, handcrafting, playing a musical instrument, leisure activities; *domestic life* household activities; and *work/employment.*	Yes; a little; no; not applicable	'difficulties'='yes' +'a little' and 'no difficulties'='no' *Domestic life* and *work/employment* were considered as one domain.
Use of ADs and prostheses	Reasons for non-use of AD	Multiple	
	Type of prosthesis (if multiple prostheses, answer required for only the one used for a long time or often)		
	Preferred solutions for ADL	AD; prosthesis; sometimes adaptive device or prosthesis; hand and affected arm and/or other body parts; with help from somebody; and not applicable	
Description of five ADs	Activity for which AD was used		
	Appearance		
	Manufacturer		
	Last 2 months of use and reasons for use/non-use		
	Frequency of use	Never; rarely; sometimes; very often; and always	
Most important AD	The choice for AD was determined by the participants' opinion on which AD was most important to them. The subsequent questions were asked specifically for the most important AD and prosthesis (if applicable).		
Use of the most important AD/prosthesis	Age of onset	<5 y/o; 5-<9 y/o; 9-<13 y/o; and 13-20 y/o	

Appendix 1 (continued)

Theme	Questions	Response options	Grouping for the analysis
	Duration	<3 months; half year; one year; several consecutive years (number of years); and alternating use, stopped for a while, used again for a period	
	Location	At home; at home and in environments with acquaintances (at school/family/friends); and everywhere (also in environments with strangers)	
Satisfaction with most important AD/prosthesis	D-Quest devices: dimensions, weight, adjustment, safety, durability, ease of use, comfort, effectiveness, overall.	Not at all satisfied; not satisfied; somewhat satisfied; satisfied; and very satisfied (a box for dissatisfaction reasons)	
	D-Quest rehabilitation services: service delivery, repairs and servicing, professionalism, services, follow-up, overall.	Not at all satisfied; not satisfied; somewhat satisfied; satisfied; and very satisfied (a box for dissatisfaction reasons)	
	Appearance of the AD/prosthesis (not part of the D-quest).	Not at all satisfied; not satisfied; somewhat satisfied; satisfied; and very satisfied (a box for dissatisfaction reasons)	'somewhat (less) satisfied'= 'not at all satisfied'+'not satisfied'+'somewhat satisfied' and '(very)satisfied'='satisfied'+'very satisfied'
Social adjustment with most important AD/prosthesis	TAPES. The social adjustment subscale consisted of four questions: "I don't care if somebody looks at my prosthesis", "I find it easy to talk about my prosthesis", "I don't mind people asking about my prosthesis", "I find it easy to talk about my limb loss in conversation." One question was adapted to accommodate a person with ULRD: "I find it easy to talk about my missing (part of) arm." The word "adaptive device/" was added before the word "prosthesis" in the questions above.	Strongly disagree; disagree; agree; strongly agree; and not applicable	
Improvement on the use of ADs	An open question, also asked about suggestions to improve the use of ADs.	Multiple	

Abbreviations and notations: AD(s), adaptive device(s); ULRD, upper limb reduction deficiency; D-Quest, Dutch version of Quebec User Evaluation of Satisfaction with assistive Technology; TAPES, Trinity Amputation and Prosthesis Experience Scale.

Appendix 2. Results of logistic regression based on cases with unilateral ULRD, with the use of adaptive devices or prostheses as outcome variable and the participants' characteristics as predictors

Past/present use of ADs or prostheses	Yes	No				
	No. (%) or Mean (SD)	No. (%) or Mean (SD)	β (SE)	P	OR	95% CI
ADs[a] (all ULRD levels)	n=154	n=47				
Age (centered at 2 y/o)	8.1 (4.3)	8.0 (6.1)	0.02 (0.04)	0.651	1.02	(0.94; 1.10)
Gender (male)	92 (59.7)	26 (55.3)	0.22 (0.35)	0.522	1.25	(0.63; 2.46)
Number of difficulties in ADL	4.4 (2.8)	3.6 (2.8)	0.12 (0.07)	0.079	1.13	(0.99; 1.28)
ULRD type (transversal)	143 (92.9)	40 (85.1)	0.89 (0.53)	0.098	2.42	(0.85; 6.91)
Constant			-0.34 (0.69)	0.622	0.71	(0.18; 2.76)
ADs[a,b] (ULRD levels higher than the wrist)	n=96	n=28				
Age (centered at 2 y/o)	8.5 (4.5)	8.6 (6.0)	0.06 (0.05)	0.233	1.06	(0.96; 1.17)
Gender (male)	55 (57.3)	15 (53.6)	-0.16 (0.47)	0.730	0.85	(0.34; 2.13)
Number of difficulties in ADL	4.6 (3.0)	3.0 (2.5)	0.22 (0.10)	0.027*	1.25	(1.03; 1.53)
Transversal ULRD (below-elbow)	85 (88.5)	27 (96.4)	-0.44 (1.12)	0.696	0.65	(0.07; 5.78)
Past/present use of prostheses	49 (51.0)	21 (75.0)	-1.08 (0.54)	0.045*	0.34	(0.12; 0.98)
Constant			1.05 (1.34)	0.432	2.87	(0.21; 39.82)
Prostheses[a,b] (ULRD levels higher than the wrist)	n=70	n=54				
Age (centered at 2 y/o)	10.0 (4.9)	6.6 (4.1)	0.16 (0.05)	0.001*	1.18	(1.07; 1.30)
Gender (male)	33 (47.1)	37 (68.5)	-0.77 (0.41)	0.063	0.46	(0.21; 1.04)
Number of difficulties in ADL	3.8 (3.0)	4.8 (2.8)	-0.01 (0.07)	0.934	0.99	(0.86; 1.15)
Past/present use of ADs	49 (70.0)	47 (87.0)	-1.25 (0.56)	0.024*	0.29	(0.10; 0.85)
Constant			0.39 (0.68)	0.562	1.48	(0.39; 5.57)

Abbreviations and notations: AD(s), adaptive device(s); ULRD, upper limb reduction deficiency; No., number of children; n, total number of children; β, coefficient showing weighting of each factor in the model; SE, standard error; P, value showing the significance; OR, odds ratio; 95% CI, the 95 % confidence interval for the estimated odds ratio; 'ever used', devices that were used in the past or currently; y/o, years old.
Percentage are calculated from the total number of 'Yes' (past/present use of ADs or past/present use of prostheses) or 'No' category (never used ADs/never used prostheses).
[a]Only youngsters with unilateral ULRD were included. Age was centered at 2 y/o. Reference categories for gender–female, for ULRD type–longitudinal ULRD, for transversal ULRD–above/through-elbow level.
[b]Included: 21 participants were with past/present use of a prosthesis, 47 participants were with past/present use of an AD, 49 participants were with past/present use of both, and 7 participants used neither. Excluded: transversal ULRD at the wrist and hand level because prostheses are not prescribed for children with wrist or hand ULRD; and longitudinal ULRD. Due to low cell numbers, the variable 'Transversal ULRD' has been excluded from the analysis conducted for prosthetic use.
*Significant P-value.